Testimony Before the Senate Committee on Government Affairs

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Thank you for allowing me the opportunity to speak to you today. My invitation to speak before you asks that I speak regarding the implementation of the Kansas Home and Community Based Services (HCBS) Waiver for children with Serious Emotional Disturbance. Before I talk about Kansas, I want to share with you for a moment my perspective from being a member of President Bush's New Freedom Commission. Last year President Bush directed the New Freedom Commission on Mental Health to make recommendations which put in place and extend the protections of Olmstead so that people with disabilities have the right to live, work, learn, and participate in their homes and communities. For the last year, as part of our Commission work, we heard testimony from families and youth across the country about their personal experiences trying to penetrate the disarray of what we call the mental health system; they told us of their efforts to access opaque and complex non systems, the difficulty to even understand service options, let alone secure access to grossly under-funded programs. Family members talked to us about discontented and overwhelmed providers, constantly changing and conflicting regulations; and they talked about losing their children to child welfare and state juvenile authorities. Parents talked about their fear, that in working to secure services they expose their family to intense community scrutiny and risk losing their child.

Parents told the Commission and Kansas parents have told our legislature that without financial resources to access mental health care; they are forced to turn to child welfare with the promise, implied or explicit that mental health services will follow. Or by default, families lose to the juvenile justice authorities when services are not available and behaviors escalate to the point that law enforcement gets involved. In Kansas, one problem with placing a child in foster care is that our child welfare system is designed to provide the child with a safe place to live, a home, usually. Child welfare providers in Kansas are not Medicaid mental health providers. In Kansas, the child welfare contractor who determines that a child in foster care has a

diagnosis, must access a mental health center for Medicaid funded services. If the center agrees that the child needs services, Medicaid funds the services. If not, the private contractor must pay for services out of the capitated payment from the state for living allowance. I can tell you this seems to deter strong advocacy for mental health services in the foster care arena. In either case when a child with mental health needs is placed in foster care, there is little involvement of the biological family in the child's mental health treatment. The child is frequently moved away and it is likely to a different mental health center catchment area, with different providers than he/she knows and who are too distant for the family, already fractured, to access; and too distant for providers to include.

The Freedom Commission has ended and the White House prepares to issue a report which may influence the development of services for the next decades. The Commission will recommend the development of full and comprehensive arrays of community services developed in concert with the families and youth who receive them. Compelling testimony and a new awareness of the national perspective has left me with an increased awareness of what the Kansas' model offers the nation in the area of children's mental health. I am excited to explain the Kansas system of services to you. I will talk about our Medicaid funded Home and Community Based (HCBS) wavier for children with Serious Emotional Disabilities (SED).

The Kansas waiver both expands the range of services offered to families of Medicaid eligible children and it expands Medicaid eligibility to those families whose incomes exceed standard Medicaid eligibility requirements in our state. The expanded range of services includes the addition of four Medicaid services: wraparound facilitation, parent support, respite care and independent living supports. Expanded eligibility means that for the waiver, only the child's income is considered, not the parents. This means that in Kansas, when a parent is faced with the imminent possibility of placing a child in a mental hospital, that parent may elect to keep the child at home in school and in the community with Medicaid funded supports and services

including the four new services and the usual cocktail of in-home therapy, case management, attendant care, etc.

With the waiver and the recognition of our legislature that children do better, are better, demonstrate remarkably better outcomes in homes than in any other setting, we are making progress. Since only two other states have adapted the HCBS waiver for children with SED (New York and Vermont) I believe I must describe, briefly how Kansas secured the waiver and is developing community based services for children.

Background: We have had the HCBS waiver since l998. It was evaluated in FY 2000 and is now in place until FY 2005. For Kansas several agendas seemed to converge at the same time. We have long practiced the Wraparound philosophy and principles of planning and serving children with parents as partners in service delivery and evaluation. SAMHSA awarded Keys for Networking, the state family organization, and Social and Rehabilitation Services one of the first national grants in l994 to develop a state infrastructure to provide children's services with family members influencing the decisions. SAMHSA had also funded two System of Care demonstration sites in Kansas, one in Wichita (an urban community) and one in rural southeast Kansas. With the demonstration sites, SAMHSA provided the means to develop children's community based services and the means to collect the data to profile service effectiveness. By l997, we knew what effective services should look like; we knew the cost per child, per kind of service to maintain children with SED in the community. This is important because one of Medicaid's requirements for the waiver is that it cost no more to serve a child in the community than in the hospital. We had the data to show cost neutrality, which is another requirement of Medicaid. We had to demonstrate that we could serve children in the community at no greater cost than to serve them in hospital placements. We had the services and we had made the decision to close a state mental hospital.

With the alliance of mental health providers, Social and Rehabilitation Services and families, organized by Keys for Networking, we moved the legislature to fund not only the waiver in

l998 but in 2000 a statewide family centered system of care with $5 million dollars to allow centers to support children's services in the community. I mention this alliance because it is not often that we are all able to agree exactly on what we want from the legislature. WE showed the legislature cost figures, we showed them charts of outcomes and we shared testimonies from families whose children had benefited from community based services.

Impact: With minimal changes and in only a few months turn around, Medicaid approved the 1998 waiver. SRS had not asked for a large appropriation. We started with $1 million. As of March 2002, the waiver is funded at $2.5 million in state funds (approx $6.5 million from all funds). In 2002, Kansas is spending an average of $12,900 for mental health service per child per year on the waiver. Hospital costs are exponentially higher. Let me share with you the following grid which delineates our service costs. Please notice that costs rise the farther the child is from his/her home and community.

Table 1
Comparison of costs in state care for children

	Per Child/per day	Per child/per year
Home and Community Based Services Waiver	$35	$12,900
Foster Care: Adoption	$39+	$13,908
Foster Care: Return to biological families	$83+ Average across regions	$29,928
Juvenile Detention Residential	$150*	$54,750
Larned Mental Hospital	$398#	$145.270
Rainbow Mental Hospital	$454#	$165,710

+Information obtained via telephone 2/10/03 from Sue McKenna, SRS
*Information obtained via telephone 2/12/03 from Ed Gray, Youth Authority
#Information obtained via fax 2/12/03 from Cornelia Jeffery, SRS

This information is important. Every time we serve a child in his/her home thru our wavier we save the state money and we save families. And we have outcomes to demonstrate the effectiveness of serving children in the community, raised by their own parents.

Table 2
Outcomes for Children with SED as reported in the Kansas Consumer Status Reports

		STATE AVERAGES					
		Caseload Size	Permanent Home %	*Without* Law Enforcement	Clinically Significant CBCL %	A, B, or C Grades %	Regular Attendance in School
FY 2002, Q3	Non-Waiver	3660	95.9%	91.4%	85%	76.7%	86.0%
	SED Waiver	1132	97.1%	90.8%	92%	78.3%	87.5%^

Table 2 shows that children on the wavier, children with the most severe mental health needs, are doing as well, often better than other children in community based settings. Both sets of children are benefiting enormously from wraparound designed arrays of individualized service plans. Kansas providers do well with children who get the services. The Freedom Commission finds that nationally, of all children who need mental health services, only 50% percent ever receive the services.

According to national prevalence estimates from the Surgeon General's report and previous National Institute of Mental Health profiles which look at 5--9% of the population having mental illness. In Kansas, 5% of 600,000 children (Census, 2000 data) suggests that 30,000 children need mental health services. Last year, the Kansas public mental health system served, 10,860 children with 4,074 of them receiving case management and other intensive services. Only 1154 receive services under the waiver. The graphs, the data shows how well we do with children we reach with community based services, all community based services. The waiver is only one way to access services. The problem is we are not reaching enough of them. Even in Kansas our juvenile jails and our foster care providers are still serving children with enormous mental health needs.

Does the waiver specifically stop the relinquishment of custody? We believe so. We believe effective community based care stops the relinquishment of custody. What I ask you to consider, though, is the apparent difficulty of other states to pursue the waiver or why there are waivers when accessing appropriate care with the financial supports to do so, should be the norm, should be the promise of this Committee.

Thank you for allowing me the opportunity to explain our program.